

# PRINCIPLES FOR THE 21<sup>ST</sup> CENTURY VISION: ARE THEY THE RIGHT ONES?

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# PRINCIPLES FOR THE 21ST CENTURY VISION

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PROTECTING PRIVACY AND CONFIDENTIALITY OF  
PERSONAL HEALTH DATA -- HIGHEST IMPORTANCE  
FOLLOW AN OVER-ARCHING CONCEPTUAL  
FRAMEWORK ENCOMPASSING ALL THE RELEVANT  
ASPECTS OF POPULATION HEALTH AND THEIR  
INTERACTIONS

FLEXIBILITY AND ABILITY TO RESPOND TO NEW  
INFORMATION NEEDS AS THEY ARISE

USE AT VARIOUS LEVELS OF AGGREGATION

COLLECT DATA A FEW TIMES FOR MANY USES

STANDARDS SHOULD BE LIMITED AND COMPATIBLE  
ACROSS SETTINGS

# 10 PRINCIPLES

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CONFIDENTIALITY MUST BE PROTECTED

AN OVERARCHING CONCEPTUAL FRAMEWORK

FLEXIBILITY TO ADDRESS NEW ISSUES

AVAILABLE IN SUFFICIENT DETAIL TO IMPACT DECISIONS

DATA STANDARDS SHOULD MAXIMIZE USEFULNESS TO  
PUBLIC HEALTH, HEALTH CARE DELIVERY, HEALTH  
STATISTICS AND RESEARCH

COLLECTED ONCE FOR MULTIPLE PURPOSES-SHARED BUT  
PROTECT CONFIDENTIALITY

AVAILABLE AT THE COMMUNITY LEVEL, LOCAL GOVERNMENT-  
-MAXIMIZE ACCESS AND USE

SYSTEM-WIDE PLANNING AND COORDINATION OF RESOURCE  
UTILIZATION

HEALTH STATISTIC NEED TO BE ORGANIZED TO  
FACILITATION HEALTH DECISION-MAKING

PUBLIC-PRIVATE COLLABORATION ESSENTIAL

# VISIONING AGENDA

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WHAT HEALTH INFORMATION WILL BE NEEDED IN THE 21ST CENTURY?

WHAT CONCEPTUAL FRAMEWORK MEANINGFULLY ORGANIZES THE INFORMATION?

WHAT APPROACHES TO COLLECTION STORAGE AND COMMUNICATION WILL MOST EFFICIENTLY GET HIGH QUALITY INFORMATION WHERE IT CAN MAKE A DIFFERENCE?

WHAT PRIVACY, CONFIDENTIALITY AND SECURITY PROTECTIONS MUST BE IN PLACE TO ENSURE THAT INFORMATION CAN BE SAFELY USED TO PROMOTE THE PUBLIC'S HEALTH?

# WHAT HEALTH INFORMATION WILL BE NEEDED IN THE 21st CENTURY?

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AT WHAT LEVELS WILL IT BE MOST USEFUL?

- BURDEN IN THE POPULATION
- ETIOLOGY OF CRITICAL THREAT
- POTENTIAL FOR INTERVENTION
- TRACKING PROGRESS
- MEASURING OUTCOMES

HOW WILL THE LEVEL AT WHICH THE INFORMATION IS NEEDED AFFECT ISSUES OF CONFIDENTIALITY AND PRIVACY?

# QUESTIONS ABOUT THE PRINCIPLES

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## ARE THEY OF EQUAL SIGNIFICANCE?

- HOW ARE INFORMATION NEEDS DEFINED?
- HOW WILL DATA BE COLLECTED?
- HOW WILL THEY BE USED?
- WHO WILL HAVE ACCESS TO THEM?

## WHAT ARE THE BARRIERS TO IMPLEMENTATION?

- CONFLICTING PRIORITIES AMONG THE PRINCIPLES
- PUBLIC UNDERSTANDING OF THE CONCEPT
- NORMS ABOUT PRIVACY

# QUESTIONS ABOUT THE PRINCIPLES

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## IMPACT ON DATA QUALITY

- WILL KEY STAKE-HOLDERS SUPPORT THE SYSTEM?
- WILL OF THE PUBLIC RESPOND OR PROVIDE DATA?

## RELATIONSHIP BETWEEN DATA SOURCES AND DATA AVAILABILITY

- WILL WE BE ABLE TO PREDICT IN ADVANCE WHAT DATA WILL BE NEEDED?
- IS IT POSSIBLE TO GET THE DATA THAT ARE NEEDED TO ANSWER THE QUESTIONS?

# HOW WILL THE DATA BE COLLECTED?

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WHAT ARE THE SOURCES OF DATA?

HOW ARE THE DATA TO BE AGGREGATED?

HOW OFTEN ARE THEY TO BE COLLECTED?

WHAT ARE THE STANDARDS FOR DATA?

# HOW WILL THE DATA BE USED?

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HOW CAN FLEXIBILITY BE INTEGRATED TO ADDRESS NEW QUESTIONS?

WHAT LEVEL OF DETAIL WILL BE REQUIRED TO IMPACT DECISIONS?

AT WHAT LEVEL (POLITICAL) WILL DECISIONS BE MADE?

WHAT DATA ARE NEEDED TO MAKE DECISIONS?

# WHO WILL HAVE ACCESS TO THE DATA?

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WHAT DATA WILL BE MADE AVAILABLE?

TO WHOM?

IN WHAT FORM?

WHAT PUBLIC/PRIVATE COLLABORATION IS NEEDED?

– AT WHAT COST?

# DATA COLLECTION ISSUES-I

## SOCIAL NORMS THAT SUPPORT COMMON GOALS

- POLITICAL ENVIRONMENT DOES NOT SUPPORT DATA COLLECTION TO ADDRESS PROBLEMS THAT ARE COMMON  
WHEN BEFORE NOW DID A PRESIDENTIAL CANDIDATE ENCOURAGE PEOPLE TO BREAK THE LAW AND NOT COMPLETE THE CENSUS?  
LEADERS IN THE CONGRESS ENCOURAGED NON-COMPLIANCE  
DISPUTES ABOUT BUDGET TO COLLECT DATA THAT MEET THE GENERAL STANDARDS OF QUALITY
- THE PUBLIC IS GENERALLY SUSPICIOUS OF DATA COLLECTION BY THE GOVERNMENT  
TELEPHONE SURVEYS GET LOW RESPONSE RATES  
PEOPLE DO NOT RESPOND TO FACE-TO-FACE SURVEYS
  - RELATIVE COSTS MAKE FACE-TO-FACE DATA COLLECTION COSTLY
- CONCERNS ABOUT PRIVACY OVER-RIDE CONCERNS FOR PUBLIC GOOD

# DATA COLLECTION ISSUES-II

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PUBLIC DOES NOT UNDERSTAND WHY THE DATA ARE NEEDED

NO CONSTITUENCY FOR PUBLIC HEALTH OR PUBLIC HEALTH DATA

ABSENCE OF AN OVER-ALL STRATEGY FOR REPORTING DATA IN A FORMAT THAT COMMUNICATES ITS VALUE

ETHNIC AND CULTURAL VALUES AND EXPERIENCE MAY NOT SUPPORT THE COLLECTION OF DATA THAT ARE SEEN AS PERSONAL OR SENSITIVE

- THESE MAY BE POPULATIONS OF SPECIAL INTEREST FOR HEALTH POLICY -- ESPECIALLY HEALTH PROMOTION

# ISSUES TO CONSIDER

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CAN A PUBLIC HEALTH AGENDA BE FORMED FROM SPECIAL INTERESTS?  
TO WHAT EXTENT WILL THE POLITICAL LEADERSHIP AND PUBLIC BUY INTO AN AGENDA

WHERE WILL THE RESOURCES TO IMPLEMENT THE SYSTEM COME FROM?  
HOW CAN WE LOOK TO THE FUTURE?

# ACTIONS TO BE TAKEN

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CREATE A CONSTITUENCY FOR PUBLIC HEALTH

RELATE THE COSTS OF NOT ACTING MORE DIRECTLY TO THE COSTS OF ACTING

INCORPORATE PUBLIC HEALTH PRINCIPLES INTO EDUCATIONAL FORUMS INCLUDING SCHOOL CURRICULA

INVOLVE HEALTH CARE DELIVERY IN THE PARTNERSHIP